

5/8/15

Building Self-Advocacy within the Family System



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May 1, 2015

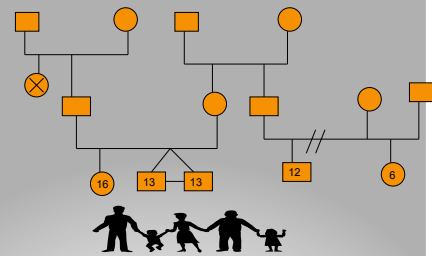
What I will speak about ...

- I am not an expert on autism, I am an expert on relationships. I hope to emphasize the importance of the family relationships, autonomy and connectedness, as well as the reality of autism within the family system
- Two different Family Therapy Theories that help us understand Family Systems
- Understand the dynamics of family systems
- Identify how a diagnosis of autism can lead to enmeshment or disengagement within a family system
- Discuss the benefits and detriments of enmeshment and disengagement within a family system
- Recognize healthy functioning and healthy boundaries in a family system dealing with the realities of autism
- A case example of a family in therapy
- I hope to have a dialogue with you today ...

Multigenerational Transmission Process Murray Bowen

- Passing patterns down from generation to generation
 - Importance of using a genograms
 - Helps us to discover family patterns and make our clients aware of them
- Differentiation - being autonomous and connected
- Self differentiation - knowing the difference between thoughts and feelings
- Anxiety: children who receive less anxiety from parents have a greater likelihood of some day achieving a level of differentiation - higher than the family-of-origin (breaking the transmission process)

A family genogram



Passing patterns down from generation to generation

- This is important to think about. For all of us, not just families dealing with the reality of autism
- Question for a family who has a member that is diagnosed with autism – Does the family have a pattern that was passed down to deal with autism?
 - What patterns are needed?
 - Healthy and effective communication
 - Healthy closeness
 - Healthy autonomy
 - Healthy support

Structural Family Therapy Salvatore Minuchin



- Provides a blueprint to help the therapist see the patterns of family dynamics.
- In all cultures, the family imprints its members with selfhood. Human experience of identity has two elements; a sense of belonging and a sense of being separate. The laboratory in which these ingredients are mixed and dispensed is the family, the matrix of identity.

Salvador Minuchin

Structural Family Therapy

Three essential constructs

- Families have **structure**
- Organized into **subsystems**
- Regulated by **boundaries**



Structure

- There is a hierarchy
 - Parent/s are in charge
 - Of their own lives
 - Of their children's lives
 - Of the family system
 - Of the family rules
 - Of the family dynamics



Subsystems

- Families are comprised of individuals and subsystems
 - Spousal subsystem
 - Parental subsystem
 - Sibling subsystem



Boundaries

- Boundaries are invisible barriers that regulate contact with others.
- They vary from rigid to diffuse
 - Rigid boundary -> Disengagement
 - Clear boundary -> Normal Range
 - Diffuse boundary -> Enmeshment
- Clear boundaries support a hierarchical structure, where parents occupy a position of leadership



Risk to the Structure

- Spousal subsystem
 - How will the couple deal with the stress?
- Parental subsystem
 - How with the parent/s deal with the stress?
- Sibling subsystem
 - How will the siblings deal with the stress?

Each subsystem is affected and each system will deal with the stress. This does not mean it will be dealt with in a healthy way that leads to autonomy and connectedness.



Risk to the Structure

Spousal subsystem

- Only about 25% of divorcing couples report seeking professional help of any kind to improve their relationship
 - (Meredith, Bahr & Goodman, 1983; C. A. Johnson et al., 2001)
 - This is for all couples. Take into consideration that a couple has now had to include the reality of autism into their couple system. They are more likely to not get the help they need.
- On average they do not seek help until about 6 years after serious problems
 - (Notarius & Buongiorno, 1992, as cited in Gottman & Gottman, 1999)" (Doos, Simpson, & Christensen, 2004, p. 608)
- A study of married couples identified the top reasons couples sought therapy
 - #1 communication-based reasons:
 - emotional affection - lack of love and affection/intimacy
 - general "communication - lack of understanding; not discussing problems



Why is this important?

The couple is the lead of the family system

- if the lead is in trouble
- the family is in trouble

If the couple is not willing to take charge of their own life and relationship/s – what happens to the relationships in the family?



What about a single parent family?

The individual parent too is the lead of the family system

- if the lead is in trouble
- the family is in trouble

If the individual is not willing to take charge of their own life and what may be happening for them – this too will have an impact on the other relationships in the family?



How do the children feel?

- Just as the parent/s did not expect autism as their guest
- The children not only did not expect it, but now wonder what happens to their own security
- If the couple or individual does not take care of their support of each other, or gaining support for themselves, then the child with autism and all other children will pay a price
- This price is lifelong ...



We only can give what we got ...

- When it comes to emotional support, we can only give to others what we ourselves have gotten from others
 - Usually those others are our parents
 - Then it is our intimate partners
- As parents, the couple is not prepared for all they will have to give when living with the reality of autism
- They will need to know what do they personally have within themselves to give
- And – what do they need to give



Parental Subsystem

- If the couple takes care of the couple, the parental system will be stronger
- If the couple takes care of the parental system, the couple system does not get stronger
 - - sometimes it gets weaker
- This is true for a single parent as well
- If the single parent takes care of his or her own needs, then their parenting will become stronger



Parental Subsystem

- First the parents need to be fully aware of themselves as a couple and advocate for themselves as a couple
- This means, going on dates, taking time for the couple, demonstrating clear boundaries that set the couple apart from the other subsystems in the family
- If the family members are going to learn to advocate for themselves, they cannot do this if they are advocating for the couple.
 - Children will sacrifice themselves to protect the couple
 - This can be magnified when a family member has autism
- If it is a single parent, that parent has to be fully aware of his or herself as an individual and the needs they have as an individual
- Once aware, the couple can identify their strengths, and then begin to use those strengths when facing the challenges of autism



Parental Subsystem

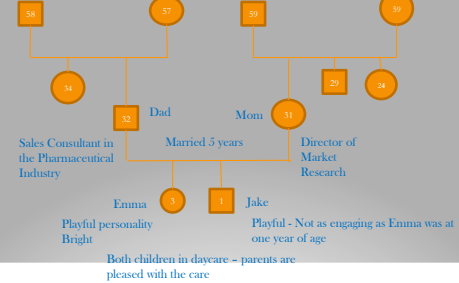
As the couple faces these challenges and parent with a united front:

- the child with autism benefits and can learn to advocate for themselves depending on where they fall on the spectrum
- the other children in the family benefit and begin to understand how to advocate for themselves
- and the couple benefits



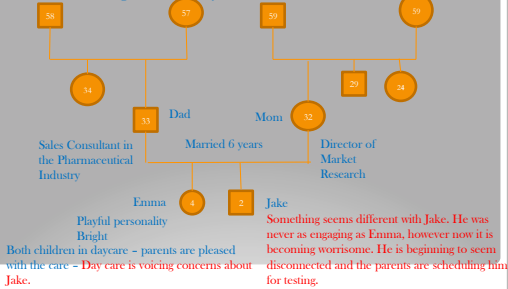
A typical family forming ...

The Worthington Family



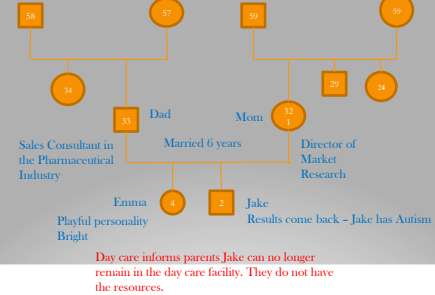
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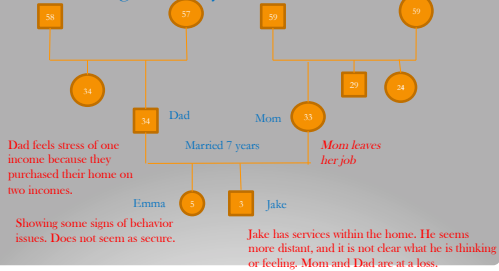
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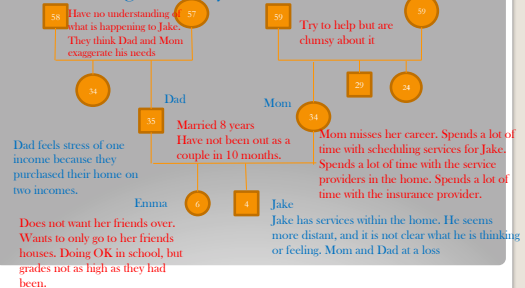
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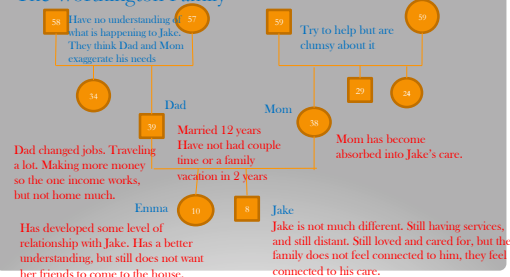
A typical family forming ...

The Worthington Family



A typical family forming ...

The Worthington Family



We have a map to help the family within the system

- However, we see the family system is struggling



The structure has changed...

- Mom and Dad are not so connected
- Parenting is Mom's main focus
- Providing is Dad's main focus
- Emma has to learn how to develop her own focus of self since Mom or Dad are not so available
- Jack does not know there is a family structure, or if he does, it is difficult to know how he understands it



The subsystems have changed...

- The couple does not so much exist
- The parents are parent and parent
- Emma is on her own, although she is more connected to Jake
- Jake never felt part of the sibling subsystem



The boundaries have changed...

- The couple started out with clear boundaries
- Autism became a part of their reality
- The couple became disengaged
- Mom became enmeshed
- Dad became somewhat disengaged
- Emma feels a bit alone
- Jake does not know of the changes



What might they do to make this better?

- Make use of family therapy
- Make use of individual therapy if needed
- Tap into all resources
- Create resources
- Make time for the family
- Make time for the couple
- Take care of individual needs
- Learn to incorporate dealing with autism into the family system

Take the time ...



- To educate extended family
- To have the courage to talk about the reality of autism - even to strangers
- To ask for help - and find out who and what your resources are - then utilize them
- To find respite, in the community, family and friends
- Take care of all sub-systems in the family - especially the couple
- If a single parent, take time for a social life.

Parents need to stop ...

- Saying "we can't do that."
 - Can't means won't
 - Parents need to find a way to do what any other families do
 - Yes ... they may need to modify, so they modify in a way that works for everyone.



Overall thoughts from families...

- Do not allow yourself, the couple, or the family to become absorbed
- Autism is an addition to the family
 - It is not the family
 - It is not their identity
- It takes effort to *not* get lost into it ...



Finding a Marriage and Family Therapist (MFT)

The American Association
for Marriage and Family Therapy

www.aamft.org

- Therapist Locator ... put in your zip code and you will get a list of MFTs in your area, and many have profiles so you can learn something about the therapist.

